

**PHYSICIANS' EXPERIENCES WITH AND ATTITUDES TOWARD NON-MEDICAL
SEX SELECTION THROUGH PREIMPLANTATION GENETIC DIAGNOSIS**

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ABSTRACT

Background: Preimplantation genetic diagnosis (PGD) is technology by which embryos, created through in vitro fertilization (IVF), can be screened for genetic conditions or traits before uterine implantation. Non-medical sex selection (NMSS) describes the use of PGD to choose the sex of a child for social, rather than medical, reasons. In the US, it is legal to use NMSS for “family balancing,” or the selection of an underrepresented sex in a family. Proponents of family balancing believe that NMSS is an expression of reproductive autonomy and is ethically acceptable on those grounds. Opponents often cite beneficence, nonmaleficence, and justice as the basis for concerns around NMSS. Physicians are thought of as gatekeepers to this technology, yet there is little research exploring the experiences and concerns of physicians around NMSS.

Objective: This study seeks to describe the experiences of healthcare providers around PGD for NMSS, with a focus on potential ethical concerns, the decision-making process, and their views on future appropriate non-medical uses of PGD, if any.

Methods: Semi-structured interviews were conducted with 8 OB/GYNs and 6 reproductive endocrinologists (REs) currently practicing in the US. Interviews focused on attitudes toward NMSS, implications of NMSS, decision-making, and non-medical trait selection (NMTS). The interviews were transcribed and subjected to thematic analysis using NVivo 9.0 qualitative software.

Results: Findings from this study reveal the nuances of physicians’ attitudes toward NMSS as well as the values that drive these attitudes. Analysis revealed that most

physicians opposed NMSS but would support their patients' wishes because of the principle of autonomy. Autonomy was also a frequent cause of ethical dilemmas for physicians struggling with values. Not all physicians identified as gatekeepers for NMSS technology. Physicians expressed conflicting preferences about the ideal decision-making process, indicating that they wanted professional societies to make clear guidelines around NMSS, but wanting to preserve patient-provider decision-making. Lastly, physicians were mostly opposed to non-medical trait selection (NMTS) because of interference in nature, parenting norms, and the importance of valuing differences among people.

Discussion: Physicians are experiencing ethical dilemmas around NMSS and NMTS. This insight should be used to inform policy around NMSS and PGD.

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RATIONALE AND BACKGROUND

PREIMPLANTATION GENETIC DIAGNOSIS

Preimplantation genetic diagnosis (PGD) is an IVF-based technology that allows embryos to be screened for certain genetic conditions prior to implantation into a woman's uterus. The embryos are created through in vitro fertilization (IVF), after which one cell from each early embryo undergoes genetic testing; only embryos without the genetic condition are implanted or frozen for later use.

Historically, PGD was intended to help at-risk parents avoid having children affected by monogenic, early-onset, lethal or life-limiting conditions, like Tay-Sachs disease or Cystic Fibrosis. PGD began in 1992 for single-gene disorders; in 2010, there were 50-150 genetic conditions that could be assessed by PGD. (Hershberger & Pierce, 2010). PGD has come to be used for adult-onset conditions like Huntington's Disease or the BRCA mutations that predispose to Hereditary Breast and Ovarian Cancer syndrome. PGD can also be used for medical sex selection, meaning the selection of embryos that would be unaffected by a disease that differentially affects the two sexes, such as an X-linked disease.

In much the same way that the early days of IVF were fraught with controversy over the wellbeing of children conceived through the technology, the existence of PGD has renewed arguments about disability rights, the humanity of an embryo, and reignited fears of eugenic potential-(Hershberger & Pierce, 2010). At the same time, an expanded PGD testing environment creates the potential for additional future uses of PGD and likely reflects an increasing acceptance of the technology (Hershberger & Pierce, 2010). Currently, PGD is offered by

approximately 75% of fertility clinics in the US (Sharp et al, 2010) and makes up 5% of IVF cases (Winkelman et al, 2014). Estimated usage ranges from 3000 to upward of 6000 PGD procedures performed in the US per year (Sharp et al, 2010; Hershberger et al, 2012). Exact numbers are difficult to obtain because there is no federal regulation of PGD and the CDC does not require statistics on PGD use or outcome (Knoppers et al, 2006).

In addition to testing for genetic disorders, two more controversial uses of PGD have emerged: HLA-typing and non-medical sex selection. HLA typing is performed on healthy embryos to select for those who can be eligible donors for sick older siblings requiring bone marrow transplant. The resulting children are often termed “savior siblings” and the use of PGD for this purpose remains highly controversial. Non-medical sex selection (NMSS), the focus of the proposed research, describes the use of sex selection techniques for any non-clinical reason. In the US, 42% of 137 IVF-PGD clinics surveyed provided non-medical sex selection (Baruch et al, 2008). NMSS is the first non-medical use of this powerful technology, making it a target for medical ethics concerns and uncertainty about its current capabilities, level of social acceptance, as well as future potential uses and their implications.

PGD AND SEX SELECTION

Sex selection refers to the process by which one attempts to choose the sex of their offspring. Currently, there are two main methods of sex selection: pre-implantation genetic diagnosis (PGD) and non-invasive prenatal testing (NIPT) or

sonogram followed by pregnancy termination (prenatal sex selection) (Levy, 2007). This research chooses to focus on sex selection through PGD only. Neither the Centers for Disease Control (CDC) nor the Society of Assisted Reproductive Technology (SART) includes the number of IVF cycles in which PGD for sex selection was performed, making the number of individuals seeking or using sex selection in the US difficult to estimate (Puri & Nachtigall, 2010). Despite this, recent research suggests that demand for sex selection seems to be increasing as it becomes more widely available and more publicized (Puri & Nachtigall, 2010).

Non-medical sex selection (NMSS) describes sex selection for social, cultural, personal, or any other non-clinical reasons. Medical sex selection is generally well-accepted among the medical and non-scientific communities whereas NMSS is often perceived as controversial. Family balancing is one iteration of non-medical sex selection. Family balancing refers to the selection of fetal sex to provide a couple with a child of the sex that is not represented or underrepresented in the family. The concept stands in contrast to the use of the NMSS to select the sex of one's first child. Fertility centers in the US offer family balancing, though most will not provide NMSS for a couple's first child (Genetics & IVF Institute; New Jersey Fertility Center). The policy on not providing NMSS for the first child comes from the official ASRM guidelines that, though not law, are generally respected by fertility clinics and other institutions (Ethics Committee of the American Society for Reproductive Medicine, 2001). Another sex selection technique, sperm sorting, is less accurate than PGD, but also less expensive and less invasive. However, as of March 2012, MicroSort, the most accurate sperm sorting technology, is no longer available in the US for any

reason. In April of 2011, the FDA stopped enrollment of couples seeking NMSS through MicroSort citing “no public health benefit” (Dahl, 2011).

Regulation and Legislation

In the United States, there is no federal regulation of PGD and, though many states have legislation around IVF, none had addressed PGD by 2006. The American Society for Reproductive Medicine (ASRM) has guidelines discouraging PGD for sex selection, however membership in ASRM is not compulsory nor can ASRM enforce its guidelines. Some physicians may, therefore, be concerned about the possibility of abuse of the technology in the absence of regulation (Knoppers et al, 2006). PGD-related legislation is difficult to conceptualize because “moral legislation” is often perceived to be in conflict with constitutional rights. Physicians would likely be concerned that any legislation would have to take care not to obstruct individuals’ constitutional rights, especially those relating to reproductive autonomy. Physicians are more likely to endorse self-regulation by relevant professional societies, rather than state or federal-level legislation (Knoppers et al, 2006).

As of 2006, PGD was permitted by law in about a dozen countries, permissible under professional guidelines in about five, and prohibited in approximately five. Approximately 16 countries allow sex selection via PGD for “medical reasons”, but not for “cultural” reasons or “family balancing,” the latter being references to non-medical sex selection. (Knoppers et al, 2006). As of 2012, no country explicitly permits sex selection. Five countries prohibit sex selection for any reason and 31 prohibit it for social or non-medical uses. Many countries do not have

laws or policies regarding sex selection; the US, for example, does not have an official policy on sex selection. Israel allows NMSS when a family has at least four children of one sex (Aghajanova & Valdes, 2012). The Genetics and Public Policy Center (GPPC) survey showed that 61% of Americans support safety and efficacy regulation of PGD and 37% desire some regulation based on moral grounds. Of note: 20% of Americans surveyed favored an outright ban on the technology. In this same survey, however, 40% of Americans supported the use of PGD for sex selection. (Knoppers et al, 2006).

Guidelines: ASRM and ACOG

In its 2001 report on “Preconception Gender Selection for Nonmedical Reasons,” the Ethics Committee of the American Society for Reproductive Medicine (ASRM) acknowledges that gender selection, by one method or another, has been occurring for centuries. Of importance to the ASRM is that attention is paid to ethical and social concerns of the practice before Assisted Reproductive Technology (ART) is widely available for non-medical use. After discussing the ethical arguments on both sides of the debate, their relative importance, and their implications, the ASRM offers four recommendations: 1) couples must receive counseling about the risks of failure; 2) couples must affirm they will accept a child of the opposite sex; 3) couples must be counseled about unrealistic expectations around gender roles and behavior; and 4) couples should be given the opportunity to participate in relevant research. Ultimately, the ASRM concludes: “Practitioners offering assisted

reproductive services are under no legal or ethical obligation to provide nonmedically indicated preconception methods of gender selection.”

Later, in a 2004 report on “Sex Selection and Preimplantation Genetic Diagnosis,” the committee reviews arguments for and against sex selection, re-addresses ethical concerns, and concludes that 1) only medical uses of sex selection override the aforementioned ethical and societal concerns; 2) non-medical sex selection is not currently harmful enough to warrant blanket prohibition; 3) PGD during IVF should not be encouraged; and 4) PGD in the absence of the need for IVF should be discouraged. The report ended with a call for the study of the consequences of the practice of non-medical sex selection.

In 2007, the Ethics Committee of the American College of Obstetrics and Gynecology (ACOG) issued a Committee Opinion with a stricter stance on NMSS than that of the ASRM. The report says “the committee rejects the position that sex selection should be performed on demand because this position may reflect and encourage sex discrimination.” Like ASRM, the committee found the use of sex selection to prevent sex-linked genetic disorders to be ethically permissible, but opposed meeting other requests for sex selection “for personal and family reasons, including family balancing, because of the concern that such requests may ultimately support sexist practices.”

NON-MEDICAL SEX SELECTION: TRENDS, CONTROVERSY, AND PUBLIC OPINION

A recent study found that 9% of PGD performed in the US was performed for non-medical reasons (Klitzman, 2008). In an internet survey of 1,197 Americans (ages 18-45), 8% of respondents claimed they would use preconception sex selection services, whereas a study of women undergoing IVF found that 40.8% would select the child's sex if it was an add-on service free of charge (Puri & Nachtigall, 2010). Additionally, the Society for Assisted Reproductive Technology reported that use of IVF-PGD for non-medical sex selection increased from 2007 to 2008 by over 5% (Ginsburg et al. 2011). These reports suggest that, despite professional recommendations to the contrary (Ethics Committee of the American Society for Reproductive Medicine 1999), sex selection via IVF-PGD is available and incidence may be increasing in the US, though overall incidence is still infrequent (McGowan & Sharp, 2013).

Sex, Gender, and Family Balancing

Sex is a biological category that can refer to chromosomal sex, genetic sex, gonadal sex, and hormonal sex. Gender is a social category characterized by physiological sex, gender identity, social identity, and sexual orientation (Seavilleklein & Sherwin, 2007). The distinction is important because equating sex with gender may disregard the reality of intersexuality, transsexuality, and homosexuality. Although sex selection sorts embryos according to their sex chromosomes (XX or XY), parents using NMSS may be intending to select *gender* rather than *sex*. At the individual level, the desire to select for a particular gender may be, at least in part, a product of unconscious, internalized gender stereotypes.

However, couples are likely not overtly considering or aware of these issues when they request sex selection (Seavilleklein & Sherwin, 2007).

At the broader societal level, many people argue that NMSS inherently, if unintentionally, perpetuates gender stereotypes and propagates harmful attitudes and behaviors, especially when those biases are subtle (Whittaker, 2011). In the US, thus far, there doesn't seem to be any indication that one sex is significantly preferred over another; if anything, there is a non-significant trend toward preference for females (Van Balen, 2006). Fertility clinics in the US and UK report that 80-90% of people using sex selection technology gave "family balancing" as their main motivation (Levy, 2007). In one study, the analysis of a large series of PGD procedures for gender selection from a wide geographical area in the USA showed that in cases where only normal embryos of the non- desired gender are available, 45.5% of the couples elect to cancel the transfer, while 54.5% of them are open to have embryos transferred of the non-desired gender, this fact being strongly linked to cultural and ethnic background of the parents.

Sex Ratio Skew

While clinical use of techniques for sex selection is gaining recognition in a powerful global market, more attention is drawn to the significant sex ratio skew evident in several Asian countries including India, China, Pakistan, and Bangladesh. As of 2005, India had a sex ratio of 107.5 males to 100 females; in China, the figure was 106.8; in Pakistan, 106.0; and 104.9 in Bangladesh. Of note, these four countries accounted for 43% of the world's total population in 2005. This is important

because according to the United Nations Population Fund, “if the continent’s overall sex ratio was the same as elsewhere in the world, in 2005 Asia’s population would have included almost 163 million more women and girls” (Macklin, 2010).). In fact, a “global marketplace” for non-medical sex selection has arisen, catering to couples who will travel to another country for a procedure because their own country forbids it. Some researchers are predicting that the sex imbalance will be self-correcting because the rarity of females will eventually increase their value and motivate families to raise their daughters (Levy, 2007). Others say that there is evidence to suggest that the sex ratio is becoming increasingly skewed (Levy, 2007).

One cross-sectional web-based survey assessed preferences for sex of children and demand for NMSS of a sample of the US general population (N=1197) in order to test the likelihood of a sex ratio skew caused by NMSS. The survey found that only 8% would use preconception sex selection technology while 74% would not. Even if the process were as simple as taking a pill, blue for a boy and pink for a girl, 18% would be willing to use this pill, but the majority, 59%, were still opposed; nearly one-fourth of participants were undecided. When asked about sex preferences, 39% wanted their first child to be a son, 19% a daughter, and 42% had no preference. The authors concluded that NMSS would not change the gender balance in the US for two reasons: not enough access and not enough interest in one sex. (Dahl et al, 2006).

In another study, of 92 couples undergoing IVF for family balancing between 2004 and 2006, 36 cycles were for females and 56 for males. Overall, this seems to indicate a lack of preference for one sex over the other. However, the patterns in

gender selection were significantly different by ethnicity. Chinese, Arab/Muslim, and Asian-Indian couples primarily selected for males, while other ethnicities (Caucasian and Hispanic) preferentially selected for females. This supports the idea that there are still cultural biases against females in certain populations and that this is an important ethical consideration in the regulation of NMSS. (Gleicher and Barad, 2007).

Given that PGD is prohibitively expensive and physically invasive it is a self-limiting procedure for the time being. This, in addition to the previously mentioned evidence, have led many researchers to predict that NMSS is not likely to have a significant effect on the US's sex ratio (Levy, 2007). Even so, there is considerable literature devoted to disputes between pro-NMSS and anti-NMSS concerning the ethical ramifications of sex selection as it relates to individual and societal conceptions of gender.

NMSS: Additional Implications

Gender selection is controversial because of possible implications on individual and societal levels (Seavilleklein & Sherwin, 2007). At the broader societal level, many people argue that perpetuating gender stereotypes propagates harmful attitudes and behaviors, especially when those biases are subtle (Whittaker, 2011). The belief that one gender is superior is *not* the most common gender-related bias held in the developed world; people are more inclined to think of the genders as having equal value, but as being suited to different roles or occupations (Levy 2007). In the US, thus far, there doesn't seem to be any indication that one sex

is significantly preferred over another; once again, there is a non-significant trend toward preference for females (Van Balen, 2006).

Possible negative consequences of family balancing suggested in the bioethics literature include reinforced/increased sexism; perceptions of children as commodities; psychological harm to non-selected children; unrealistic pressure on sex-selected children to conform to gender roles; undue physical burden on women; unjust allocation of medical resources; destruction of healthy embryos; exacerbation of socioeconomic differences; and conflict with the parental ideal of unconditional love for children (Jones, 2001; Sharp et al., 2010). Those in favor of NMSS and against restrictive regulation believe in the supreme importance of reproductive autonomy. Many physicians who offer NMSS believe it benefits the families because it gives them a child that enhances the experiences of his/her siblings or allows for better family planning. Physicians also value NMSS because there is significant cultural pressure on some women to have a child of a specific sex, and NMSS may save them or their children from certain harms (Sharp et al., 2010).

CONCEPTUAL FRAMEWORK

This study aims to understand the perspectives of physicians on the ethics of NMSS as well as their experiences, and, as such, this study's conceptual framework borrows heavily from bioethics' "moral experience framework." Moral experience, as defined by Hunt and Carnevale (2011), encompasses a person's sense that his/her important values are being realized or thwarted in everyday life; this

includes the person's interpretation of lived encounter(s) as falling within the spectrum of right-wrong, good-bad, or just-unjust (Hunt & Carnevale, 2011). A situation characterized by ambivalence may also be a moral experience if the experience is relevant to a person's values. Furthermore, a "diffuse feeling of unfairness" is as much a moral experience as an "acutely felt sense of manifest injustice" (Hunt & Carnevale, 2011). The major principles of bioethics may inform the types of values that physicians draw on, including values related to autonomy, justice, and beneficence. The framework has been used previously in studies of the moral experience of healthcare professionals with patients, the pharmaceutical industry, and hospice care (Gibson et al, 2012; Osborn, 2012; Carnevale, 2013).

REPRODUCTIVE AUTONOMY AND REPRODUCTIVE DECISION-MAKING

Proponents of NMSS, ranging from physicians to researchers to ethicists, believe that reproductive autonomy, which is the inability of the government to infringe upon the right of individuals to make reproductive choices for themselves, would be jeopardized if NMSS were illegalized or restricted. Opponents believe that reproductive autonomy is trumped by human rights principles, relevant if detrimental effects of sex selection are recognized as a global issue (Whittaker, 2011). The significant role of reproductive autonomy cannot be overemphasized; in a comparison of the attitudes of primary care providers and reproductive endocrinologists, "patient autonomy" was the single most commonly mentioned ethical argument both *for* and *against* sex selection (Puri & Nachtigall, 2010).

In light of the possible effects of the use of NMSS, it is important to understand the context in which couples and providers make decisions about reproductive technologies. Although research on NMSS is more limited than research on other prenatal testing procedures, findings from a series of ethnographic interviews with couples pursuing NMSS via PGD suggest that some couples recognize it as an ethically complex decision and experience ambivalence about its acceptability (Sharp et al, 2010). Further research is needed to characterize the moral ambivalence, if any, of the NMSS referrers and providers.

PHYSICIANS' ATTITUDES AND PROFESSIONAL ETHICS

The decision to use or provide access to reproductive technologies, especially PGD, may be marked by complex moral, ethical, and societal issues. Some researchers believe that there should be limits on this technology, but there is no consensus as to how this might reasonably be done, if at all (McMahon, 2004). In its ethics consensus statement, the ASRM concluded, that despite “serious ethical concerns,” they would need “more clearly persuasive ethical argument[s]” or “stronger empirical evidence” for harm before they would consider creating policies to prohibit or condemn nonmedical preconception sex selection (Puri & Nachtigall, 2010). With ambiguous guidelines and a lack of legislation, physicians report that often they are individually making ethical, even legal, decisions based on their own judgments (Caldas et al, 2010).

In a cross-sectional survey of Brazilian OBGYNs' views on SS via PGD, Caldas et al found that 36.4% felt that NMSS is always the couple's choice, 42.6% believed it

should be the couple's choice only in certain situations, and 17.6% did not believe that NMSS should ever be the couple's choice (2010). A large majority of these physicians felt positively about PGD use, so the differing opinions seem to be a function of considering NMSS rather than a more general problem with the selection of embryos. For those who opposed NMSS, 70% chose the explanation that "all children are welcome" and almost 20% chose the explanation of "unnatural." Other reasons for opposing NMSS included "not wanting to play God," and concerns about a sex-ratio imbalance, though these options were chosen by fewer participants (9% and 3% respectively). Of note, male OBGYNs in this study were twice as likely as females to be in favor of SS (Caldas et al, 2010).

In a recent survey of 220 US internists, about half (49.4%) would not recommend PGD for non-medical sex selection, 45.4% were unsure, and only 5.2% would recommend PGD for NMSS. Of the 220, only 4.9% had actually suggested PGD for any indication to patients and only 7.1% felt capable of answering questions from patients (Klitzman et al, 2013). These findings suggest the presence of a great deal of uncertainty and ambivalence about the use of PGD, both in the context of NMSS and for medical purposes among internists. The researchers use their findings to emphasize the importance of future research in understanding how physicians make decisions about PGD referrals as well as what variables related to characteristics of providers influence referrals (Klitzman et al, 2013).

Puri and Nachtigall's interview-based study comparing primary care physicians' (PCPS) and physician sex-selection technology providers' (SSTPs) attitudes toward sex selection found SSTPs were in favor of sex selection as an

expression of reproductive rights, as a sign of female empowerment, as a method of family planning and preventing unwanted pregnancies, and as a way of minimizing abuse of wives or neglect of children. PCPs were more cautious about NMSS, questioning whether women were actually exercising autonomy when under significant family pressure; they did not see NMSS as a solution to domestic violence. They were concerned that SS technologies were invasive interventions without therapeutic indications, that they could contribute to gender stereotypes, and that there could be detrimental psychological consequences for non-selected children (Puri & Nachtigall, 2010). Still lacking in the literature are studies that elicit the opinions of the clinicians who are actually most likely to engage in assisted reproductive technology (ART) and NMSS practices (Caldas et al, 2010).

One study of fertility clinic directors gave them ethically complex case scenarios to evaluate. For each scenario, the director had to decide whether (s)he would offer treatment. One of the scenarios was based on non-medical sex selection. Those who did not support treatment cited their philosophy of medicine, including concerns about misuse of medical technology or use for non-disease conditions, both concerns related to the principle of justice. Some described the technology as unethical or a “slippery slope” to greater misuse. They were also concerned about discrimination, particularly sexism and the implications of sex selection on sex ratios and the value of women in society. Yet, many participants who did not support the treatment permitted patients to use the technology out of respect for patient autonomy, suggesting that this value plays a powerful role in physicians’

decision-making (Stern et al, 2003). Clinic directors may have resolved their discrepant views by allowing the value of autonomy to trump their other values.

THE ROLE OF THE PHYSICIAN IN DECISION-MAKING

Physicians are ideally positioned to be the gatekeepers for reproductive technology and currently function in that capacity in many regards. In 2004, health care providers were already reporting that couples often asked whether sex selection was possible (Sauer, 2004). Currently, physicians make recommendations and referrals with minimal and often conflicting guidance from medical societies. It is clear from the relevant research that physicians differ in their attitudes by field and possibly by gender, but little is known about the underlying principles or values used by physicians when making decisions about ethically ambiguous issues (Caldas et al, 2010; Puri & Nachtigall, 2010). The views and practices of IVF providers and obstetricians could be informative for creating useful practice guidelines and elucidating ethical concerns (Klitzman et al, 2008). In Puri and Nachtigall's study, providers reported that, though infrequent, the accompanying emotional impact ensured that sex selection cases were memorable (2010).

PGD, NMSS, & THE "SLIPPERY SLOPE"

Scientists and non-scientists alike have voiced concerns over the possible "slippery slope" from NMSS to the ethically charged idea of what some have called "designer babies" (Dahl, 2003; Jones & McMahon, 2003; Klitzman et al, 2008). The "slippery slope" refers to the first non-medical use of PGD, NMSS, leading to future

non-medical uses, specifically non-medical trait selection. Unlike the eugenics movements of the twentieth century, during which there was a broader social agenda of the state to determine who was genetically fit to reproduce, PGD decision-making today seems to occur on an individual level (Hershberger & Pierce, 2010). The German Institute for Demoscopy surveyed 1044 men and women (16 and older) from the general population about attitudes toward non-medical trait selection. 80% disapproved of “designer babies.” The 20% who did not disapprove were asked for which characteristics they would select: 45% would select for intelligence, 28% for sex (6% of the entire sample), 17% for physical prowess, 13% for height, 12% for artistic talent, 4% for hair color, and 4% for eye color (Dahl, 2003).

In 2013, a nationally representative sample of U.S. residents (aged 18-75) (N=1066) were surveyed online about their perspectives on PGD. The majority of respondents approve of its use for identifying early-onset life-limiting conditions. However, only 21% support its use for sex selection. Asked about other non-medical traits, 19% support the use of PGD for personality traits, 15% for physical traits, and 13% for sexual orientation. Compared to women, men were two to three-fold more likely to endorse PGD for sex selection or non-medical traits. Also significant is the finding that Asians were four times more supportive of PGD for sex selection compared to Caucasians. Those with a graduate degree (college and above) were more opposed to sex selection and non-medical trait selection compared to those without a college degree. In general, respondents were more supportive of PGD for genetic diseases if they were aware of PGD prior to the survey (Winkelman et al,

2014). As previous literature shows, there is variation in physicians' attitudes towards NMSS; it may be that some of these attitudes are also relevant in considering policies related to other non-medical traits (McMahon, 2004).

SIGNIFICANCE

There is a dearth of literature dedicated to eliciting the attitudes and perspectives of healthcare providers around the ethics and use of PGD for NMSS. The significance of this research is multi-tiered with potential significance at the level of the individual as well as society, both locally and globally. Research in this area may impact practice guidelines as well as providing information about the moral experiences of physicians in this area. Puri and Nachtigall call for research on the perspectives of physicians involved in or aware of sex selection in order to ground ethical debates within the experiences of clinicians in different specialties (Puri & Nachtigall, 2010). Furthermore, understanding how physicians decide on hypothetically "appropriate" non-medical traits may suggest that the values influencing where they "draw the line" overlap with or diverge from those that influence attitudes toward NMSS. Unlike previous studies, this study attempts to elicit, rather than provide, the reasons for physicians' attitudes toward NMSS as well as seeking a more nuanced understanding of those attitudes. Future quantitative work in this topic would be informed by a deeper knowledge about physicians' attitudes and preferences and would inform researchers about the best questions to ask in follow-up. Findings may influence patient-provider communication around decision-making and, eventually, communication norms may influence policy. This

research can illuminate larger societal implications if use of NMSS technology becomes more widespread, especially the extent to which people are grappling with the effects of individual decisions on broader issues.

OBJECTIVE AND SPECIFIC AIMS

The American College of Obstetrics and Gynecology (ACOG) and the American Society for Reproductive Medicine (ASRM), the professional societies most relevant to physician populations studied here, disagree in their recommendations around the use of PGD for NMSS. However, both appreciate that there are complex ethical concerns inherent to the practice, the recognition of which forms the basis of their recommendations. The ASRM, in their professional statement on NMSS, calls for more research into the consequences of this practice. Neither society makes clear the role of the HCPs, who are positioned to be gatekeepers of the technology, nor is there a consensus as to what role HCPs prefer to play in this process. Recognizing that NMSS is the first non-medical use of PGD, it is essential to elicit the attitudes and concerns, if any, of HCPs, in order to ground ethical debates about sex selection as well as allowing professional medical organizations to clarify their guidelines.

This study seeks to describe the experiences of healthcare providers around pre-implantation genetic diagnosis (PGD) for non-medical sex selection (NMSS), with a particular focus on potential ethical concerns, their role in the decision-making process, and their views on future appropriate and inappropriate non-medical uses of PGD.

Specific Aim 1: To describe the experiences healthcare providers (HCPs) have had around non-medical sex selection (NMSS), as well as their attitudes toward and perceptions of previous experiences and hypothetical NMSS scenarios.

Specific Aim 2: To describe perceptions HCPs have, if any, about the implications of NMSS.

Sub-aim1: To elicit perceptions of individual-level implications.

Sub-aim2: To elicit perceptions of societal/global-level implications.

Specific Aim 3: To explore HCPs' perceptions about NMSS decision-making and their current and preferred roles in the process of decision-making.

Specific Aim 4: To elicit other traits considered by HCPs to be appropriate (or not) for selection through PGD and explore how they make those distinctions.

METHODS

STUDY DESIGN

This is a qualitative, cross-sectional study in which one-time semi-structured interviews were conducted with a purposive sample of OB/GYNS (n=8) and reproductive endocrinologists (REs) (n=6). Interviews were coded in an iterative process using a codebook that evolved as themes emerged (**Appendix G**).

Interviews took place by telephone to facilitate recruitment beyond a limited geographical area. This qualitative study is one of the first in which attitudes and experiences of these particular medical specialties have been elicited. The

qualitative design allowed flexibility during data collection as well as the potential to capture unanticipated themes through in-depth analysis.

STUDY SAMPLE AND RECRUITMENT PROCEDURE

Participating physicians were recruited via cover letters (**Appendix A**) explaining the study and received an opt-out letter in a pre-paid envelope (**Appendix F**). Addresses were obtained from the websites of the American College of Obstetrics and Gynecology (ACOG) and the American Society for Reproductive Medicine (ASRM). Two rounds of letters (n=120 and n=40) were sent out to physicians chosen at random from across the United States. The interviewer (NH) followed-up by phone two weeks after each mailing. Eligibility was confirmed and interview times were scheduled during the phone call. Consent forms (**Appendix B**) were sent (via fax or email) to participants before the day of the interview so that verbal consent could be obtained on the phone just prior to the interview.

Because response rate was poor after several months (n=6; <5%), a secondary recruitment took place in which cover letters were emailed to the directors of Reproductive Endocrinology and Infertility Fellowship programs contained in the ASRM and Society for Reproductive Endocrinology and Infertility, Inc(?) Directory of Fellowship Programs. Snowball sampling was also used to reach a greater number of providers. Participants were eligible if they were English-speaking physicians who self-reported that they were currently practicing medicine within the United States as an OB/GYN or RE, or were practicing as a resident/fellow specializing in OB/GYN or reproductive endocrinology. Interviews

were scheduled by email and consent forms were emailed to residents before their interview.

Prior to each phone interview, verbal consent, including permission to record the interview, was obtained. Some demographic information was collected through a brief questionnaire (**Appendix E**) given before the interview including the physician's age, sex, medical specialty, type of workplace, characteristics of their patient population, broad geographic location, number of years in practice, and whether or not the physician was a parent. Furthermore, the physician was asked about the strength of his/her feelings toward NMSS, and whether he/she had been actively involved in the NMSS debate or tried to change policy (**Tables 1 & 2**). Participants were not compensated for their time.

STUDY INSTRUMENT AND INTERVIEW PROCEDURE

The lead investigator (NH) conducted all of the interviews, which lasted approximately 30 minutes each. Interviews were semi-structured and guided by open-ended questions and follow-up probes designed to allow the interviewer to clarify statements or to invite elaboration (**Appendix C**). The interviews were flexible and participants were permitted to elaborate on any topics in the sequence they wished. The interviewer allowed the participants to lead the discussion so that topics of particular salience to the participant were explored, however the interviewer redirected the interview to ensure key topics were covered. The content or phrasing of questions was clarified based on areas of confusion. Certain questions

received more or less focus in each interview depending on their relevance to the specialty of the participant.

During the interviews, participants were asked to share a narrative of their clinical experiences with NMSS as well as their personal feelings and actions in these situations. They were also asked how they address NMSS requests; what ethical issues they believe are raised by NMSS, if any; and their attitudes toward decision-making around NMSS; and regulation of the use of NMSS. Many of these themes parallel themes from Puri & Nachtigall's study (2010) because they are proposed to be highly relevant and important themes for PCPs (including OBGYNs) and sex selection technology providers (SSTPs) (including reproductive endocrinologists). Interviews were audio-recorded and transcribed by professional transcription services. All interviews were de-identified through the replacement of personal identifiers with interview identification numbers and demographic data is only reported in aggregate. See **Appendix D** for procedure flow chart.

ANALYSIS

A qualitative analysis was appropriate for this study as evidenced by previous successes in the investigation of other ethical controversies in reproductive medicine (e.g. prenatal diagnosis, use of IVF technology) (Puri & Nachtigall, 2010). A qualitative study is preferable when there is little known about the experiences and attitudes of a stakeholder group, especially around an ethically complex issue. The experiences and attitudes of physicians toward NMSS via PGD are poorly understood; the goal of thematic analysis was to gain an in-depth

understanding of the context surrounding this phenomenon, particularly as it concerns ethics. Hunt and Carnevale believe that their moral experience framework is compatible with qualitative, constructivist research (2011). Constructivism defines knowledge as socially constructed, signifying that the researcher and participants co-create the study's results and that no a priori theory can capture the phenomenon of interest. Hunt and Carnevale acknowledge that a researcher studying the moral experiences of a group should realize that they cannot capture the complete experience, but can attempt a Gestalt based on fragments and cautiously evaluate the normative implications of the work (2011).

Analysis was driven by the codebook, which itself was modeled on the interview questions and themes relevant to the ethics-related conceptual framework. The initial codebook was also based on themes and constructs in relevant previous literature. Transcripts were coded in an iterative process throughout data collection and refined throughout the analysis process based on emergent and/or unanticipated themes. The earliest transcripts were coded based on the preliminary codebook, with existing codes modified or removed as more transcripts were analyzed. Transcripts were assessed for convergent and divergent themes. The main content areas were explicitly interrogated and examined for common, emerging trends. Codes were often compared and consolidated into major categories. Illustrative quotes were used to define codes and describe recurring themes. Analysis of sub-groups was tentatively attempted with the understanding that thematic saturation had not been reached at 14 transcripts and therefore these comparisons may change as more data is collected. Transcripts were

coded using NVivo software to assist with data management and analysis of thematic content.

Twenty percent of the transcripts created to date were double coded by another investigator using the same codebook as the primary coder. Thus, of the first 14 transcripts, the second coder independently reviewed and coded three (approximately 20%) to examine and resolve discrepancies with the primary coder to ensure consistent application of the codes for reliability. Thus far, discrepancies have been readily resolved. This study is ongoing and recruitment will continue with the goal of reaching theoretical saturation and a sample of 30-45 individuals. After thematic saturation is reached, the second coder will code additional transcripts.

Table 1. Physician Characteristics

Physician Characteristics		
Age		
	N	~%
30-39	7	50
40-49	2	14
50-59	2	14
60-69	3	21
Gender		
	N	~%
Male	6	43
Female	8	57
Specialty		
	N	~%
OB/GYN	8	57
RE	6	43
Region		
	N	~%
Northeast	7	50

Midwest	1	7
West	2	14
South	4	29
Years in Practice		
	N	~%
<10	7	50
10 or more	7	50
Parent (Y/N)		
	N	~%
Yes	12	86
No	2	14
Strength of Feeling toward NMSS		
	N	~%
Not Strong	3	21
Somewhat Strong	6	43
Strong	1	7
Very Strong	4	29
Ever Involved in Debate/Policy		
	N	~%
Yes	1	7
No	13	93

Table 2. Typical Patient Population Demographics

Patient Population Demographics		
	N	~%
Type of Workplace		
Clinic	2	14
Private Practice	3	21
Hospital	3	21
Other	0	0
Combination	6	43
Majority Caucasian (Y/N)	N	~%
Yes	6	43
No	8	57
% on Public Assistance		
	N	~%
<50%	9	64
50% or greater	5	36
% Annual Income > \$200K		
	N	~%
<10%	5	36
10% or greater	9	64

Majority Age Group (Years)		
	N	~%
<25	2	14
25-35	3	21
>35	9	64

FINDINGS

Overall, our participants were personally opposed to non-medical sex selection, though many supported patients in their professional capacity. Almost all physicians had encountered requests for NMSS, whether it was for family balancing, a first child, or both. Thus, many were able to discuss their attitudes based on actual personal experience with requests. If physicians hadn't experienced a particular scenario, they were asked to imagine their response and feelings to a hypothetical scenario. Regardless of whether the scenario was hypothetical or actual, physicians drew on common values to explain their attitudes, feelings, and decision-making around the request..

VALUES INFLUENCING VIEWS ON NMSS

Medical Ethics Principles

Values refer to one's judgment of what is important in life. All physicians spontaneously referred to their values when discussing their attitudes toward NMSS, and all were asked specifically to consider the values and beliefs they held

that influenced their personal and professional views on NMSS. Most of the values, whether mentioned without prompting, or raised in response to later questions, drew on medical ethics principles: justice, autonomy, beneficence, and nonmaleficence (“do no harm”).

Autonomy seemed to be the value or ethical principle cited most often by all the participants. Even though 10 out of 14 physicians were clearly not in favor of NMSS, more than 50% of them would support a patient in obtaining NMSS (though the number varied between the “family balancing” and “first child” contexts) because of their respect for patient autonomy and reproductive decision-making. When physicians’ personal views and professional actions around NMSS were at odds, they were likely to explain the inconsistency by promoting the importance of patient autonomy. Paradoxically, the belief in patient autonomy was also the most likely value to cause the physician to feel conflicted.

“And so, I do feel really strongly that people should be able to choose parenthood or lack of parenthood. And, so, I do really feel compelled by personal choices, about families, but I feel really conflicted when those personal choices come down to a choice between a male and female child.” (12; OB/GYN).

12 of 14 physicians cited “justice,” directly or indirectly, as a value or concern. Among our participants, this principle was only used in the context of explaining negative attitudes toward NMSS. Similar themes in this category included allocation of medical resources, unequal access, and financial burden on the patient.

"My concerns about it are mostly with distributive justice and the idea that the only people who would be allowed to do that are the people who have far more money to be able to afford it." (9; OB/GYN).

Another important theme within the principle of justice was the idea of NMSS as unnecessary and a frivolous or irresponsible use of IVF technology.

"And, you know, choosing to have one gender over another for some simple reason of, again, like "I don't want that," does not seem to me to be a valid use of very expensive and very limited health dollars, unless it's coming from your pocket. And it's not something I think the technology was meant to be used for." (11; OB/GYN).

Nonmaleficence, or "Do No Harm" (as most physicians referred to it), was often used to explain why a physician professionally discouraged NMSS through PGD. Participants were most likely to refer to this principle, the basis for the Hippocratic Oath, when discussing the physical risk of undergoing IVF, especially in cases where the patient was otherwise fertile.

"Well, I mean I think that it's part of our Hippocratic Oath to do no harm and I believe that doing something for—I don't believe that having a child of the gender that you want is enough to justify the harm of the risks of PGD and IVF, or selective abortion, et cetera, so that, even though there are people who will do that, I think responsible

physicians have to make sure that they follow that principle of “above all, do no harm.” (3; OB/GYN).

The last of the medical ethics principles is beneficence. This was infrequently mentioned, less so than the other three principles, but used in the context of wanting to help patients or promote the patient’s best interest. In this way, beneficence was used either to justify supporting the patient’s interest in NMSS or discouraging it in order to better serve the patient’s best interest.

“But, you know, I just don’t believe in patient abandonment, regardless of whether I agree with the issue or not.” (6; OB/GYN).

“I went into this field to give patients that want to have children the ability to have children, not the ability to have boys or girls.” (7; RE).

Gender Equality

Though they are often interrelated, gender equality was the second-most often mentioned value after the medical ethics values. This was articulated by a majority of physicians, almost equally among men and women. Physicians talked about this value in relation to NMSS in general, to family balancing, to decision-making, and to non-medical trait selection. This value was often cited when a physician’s personal and professional beliefs were at odds; but when citing the value of gender equality, more often than with values related to the medical ethics

principles, physicians let their personal value guide their professional recommendations and responses.

"I think anyone of my generation was sort of raising in the feminist-- we all have to have some sort of female solidarity in getting each other, all of us to be able to be equal to men, and you know, I think it's very hard for me to detach that part of myself from my feeling about [a couple] not wanting a girl.... I just think that, you know, I can't help but want to defend that baby girl in that situation." (6; OB/GYN).

Personally, I find that distasteful. I think -- you know, like I said, as a woman, I find it distasteful that one gender would be preferred over the other and probably, personally that my other gender would not be preferred. (8; OB/GYN).

POTENTIAL HARMS OF NMSS

Individual/Couple-Level

There were two main harms expressed by physicians at the individual-level: unnecessary, invasive procedures and disappointment of parental expectations.

But I don't consider sex selection on demand to be a sufficient reason to take those risks and to put patient autonomy above patient harm. (3; OB/GYN)

"I think that we have huge expectations that aren't always met and I think once you select for something you envision, one can end up very easily disappointed." (1; OB/GYN).

Provider/Profession-Level

In general, physicians were most likely to report "no harms" for themselves or their colleagues at this level. However, they did feel that acting against one's values or code of ethics was a potential harm of allowing NMSS.

"But there's an implication on me as a provider, by doing something that I don't believe in, not only in terms of, in general, discriminating against the embryos that are female, but discriminating against the woman because I'm enabling or facilitating the male discrimination in that relationship..." (13; RE).

Society/Global-Level

There were two common harms at this level that physicians believed applied to the US as well as to other countries. The first was perpetuation of gender stereotypes and attendant sexism. Eleven participants (4 males and 7 females) spontaneously brought up the value of feminism or gender equality when presenting their opinions on NMSS. Often this was in the context of being distressed by the valuing of one sex over another.

"And so because I'm sort of committed on a philosophical level and also in the work that I do to enhance reproductive choice for women and enhance their access to care, I think that gender balancing almost always ends up in discrimination against women and the female sex." (13; RE).

The second harm discussed is the possibility of a sex ratio skew. Physicians generally agreed that this was not currently a problem in the US; still, 12 of 14 participants spontaneously mentioned the sex ratio when discussing population-level implications. Thus even though it was not seen as a currently pressing issue, it was predicted by participants to be one of the most important should NMSS become widespread.

"I think there are parts of India, there are parts of China, there're probably other parts of the world in which this creates a real problem for the population because it really throws off the number of men versus women in the population, which creates significant societal problems. I think in the United States, we don't have that issue, so, in that light, I guess I don't feel like it's something that -- I wouldn't offer, but I still find it personally distasteful." (12; OB/GYN).

"You destroy the rough balance that exists. I mean, we know at conception, more males are conceived, more males are born. But by age one and every year thereafter, there are more girls or women.... That's necessary for preservation of the species." (1; OB/GYN).

POTENTIAL BENEFITS OF NMSS

Individual/Couple-Level

Physicians proposed several benefits of NMSS for the individual or couple seeking it. They saw it as a part of family planning and an expression of reproductive autonomy. In either family balancing or choosing the sex of the first child, they acknowledged that the couple comes away with a wanted child who otherwise wouldn't exist.

"I mean, I have to say to you that we are blessed, you know, with children of both genders, and we also have many, many friends that have children of only one gender. So I can clearly understand...the thrill of having, you know, children naturally of opposite genders." (8; OB/GYN).

Provider/Profession-Level

As with harms, physicians were less able to elucidate benefits of NMSS at the provider-level. Most agreed that other than satisfying their patients, they didn't see any benefits to themselves or their profession.

"Other than like giving people what they want. I don't know what the value is otherwise." (2; OB).

Society/Global-Level

On a societal-level, one physician noted that using NMSS was the “lesser of two evils” with the alternative option being termination of pregnancy. Otherwise, our physicians were unable to see any benefits.

“So some would argue that, well, it’s a lot -- it’s a lot less morally reprehensible, it’s more ethical to do IVF with PGD than it is to practice, you know, abortions on babies that are already in utero or infanticide. And I think that that’s probably true.” (13; RE).

VALUES IN CONFLICT

Twelve physicians expressed some degree of inner conflict around non-medical sex selection. Seven participants identified clashes between their values around respect for patient autonomy and their values of justice or nonmaleficence. For example, physicians want to respect their patients’ desires while promoting their best interests, but sometimes found the two ideals to be at odds. Many times, these conflicts were resolved by a “trump,” meaning that the provider allowed one of his/her values to outweigh another. This could work in either direction, allowing the provider to justify supporting or discouraging their patients in seeking NMSS.

“At the end of the day, I think that individuals, men and/or women, should have the ability to reproduce with autonomy. I believe that. That said, they need to reproduce with a sense of social responsibility and a sense of social justice. When you reproduce

with a goal of discriminating on the basis of anything, but certainly gender, I don't think it falls within the boundaries of social justice. And that's why I'm against it. So I think they should have lots of choice, but I don't think it should be the choice of discrimination on gender." (13; RE).

"I'm someone who strongly believes in choice.... I wouldn't want to restrict a woman's ability to choose anything that would affect her health....And like it or not, pregnancy affects a woman's health, or has the potential to affect her health. So, I'm not the person who should decide whether or not she can or can't do that. I don't like performing terminations for someone on the sole basis of gender, but I know I've done it, sometimes because the patient is a little cryptic, but it's obvious why someone's doing it sometimes." (1; OB/GYN).

There was no apparent difference between the two specialties in the values most often in conflict, but OB/GYNs were more likely to discuss having value conflicts at all than REs.

Another type of conflict, brought up by at least five physicians, referring mostly to actual experiences rather than hypothetical ones, was the struggle inherent in using NMSS as a solution for the problem of an individual patient and, in doing so, reinforcing the status quo or propagating a larger social problem. Usually, these were seen as paradoxical situations in which using NMSS benefitted the individual while maintaining the societal-level problem that had been the reason for NMSS in the first place. Physicians who discussed this phenomenon expressed

significant distress over it, either because they were concerned for the welfare of their patient, or because they were unwilling to reinforce problematic social structures.

For example, physicians often worried about their patients being subjected to marital abuse if they had a child of the “wrong” gender. While they wanted to protect their patients, they knew that NMSS was not actually helping the problem and would arguably be reinforcing it on a larger societal scale.

“Or, you know, ‘you’re going to be beaten because [you didn’t have the right gender]...’ you know, but that—I mean the problem is not the gender, the problem is that person, so I don’t think [NMSS] is a solution.” (2; OB/GYN).

“And valuing one over the other just based on gender is flawed because the opportunities that are open to either gender have evolved.... I feel it’s important that every potential patient be made to realize that they don’t really need to choose one or the other based on their [the child’s] chances of success.” (7; RE).

REGULATION AND DECISION-MAKING

Physicians were asked to consider who is responsible for NMSS at their place of work, who they felt *should* have the power to make NMSS-related decisions, and what kind of policy they themselves would institute if given the opportunity. All physicians said that the current method of decision-making at their place of work was adequate. The majority of NMSS-related decisions are made by individual

physicians or the providers of one institution making decisions as a group. Some were uncertain of the policies where they worked and several reported there was no official policy.

As to who or what the physicians would ideally prefer, there was a lot of uncertainty and several answers that included contradictions. Many of our physicians believed that NMSS should be regulated by a professional society, like ASRM, yet didn't feel that that was a realistic or truly preferable solution. They felt that an issue that could have population-level effects or cause harm to society should be in the purview of the professional societies. Simultaneously, they worried that a societal or governmental policy would be rigid and interfere with the evolution of the technology as well as the patient-provider relationship. They also felt that the professional societies were unlikely to take a position on a controversial topic unless an extreme problem surfaced, like a significant sex ratio skew.

"I think it makes all of our lives much easier, if we have a professional society passing down a guideline. On an issue as sensitive as this, I just don't see that happening.... it ultimately is very often left to the individual provider, which I think is much harder." (6; OB/GYN).

"It would be nice if the medical society came up with a consensus statement, but there's so many viewpoints to take into account." (7; RE).

"I think the professional society should probably have some sort of involvement in this and generally when things are decided at that level there's a uniform practice across the nation. And then, you know, you can keep things in check." (5; RE).

However, simultaneously, most did not want regulations from a professional society or government body that would restrict the physician's judgment. The type of decision-making that physicians found most ideal was joint decision-making between the patient and provider.

"I don't think there should be an organization, because anytime one has administrators making medical decisions, it's anathema to my personal beliefs. I think physicians should make medical decisions in concert with their patients, not have some legislator decide what should be done just based on whatever ideological beliefs that legislator has. I think one of the big problems in medicine is that you have individuals who have no medical experience other than going to the doctor, making decisions. So, in general, it should be left to the patient and her physician." (1; OB/GYN).

When asked what policy they would prefer, several physicians favored a total ban on NMSS, while others preferred less restrictive regulation. A few physicians compared NMSS to cosmetic surgery and preferred that it be legal so long as the financial burden was on the patient, not the insurance. A small minority were so uncertain that they were unable to express a preference; often this was because they didn't know how their colleagues felt about NMSS. One OB/GYN suggested

monitoring the number of males and females born through NMSS and stepping in only if the ratio strayed too far from the norm.

GATEKEEPING

Most of the physicians were asked whether they felt themselves or their colleagues to be in the position of “gatekeeper” to the technology of NMSS via PGD. Twice as many physicians said yes as said no, with some answering both yes and no; one spontaneously created the term “gate regulator” which he felt to be more accurate. All those who didn’t identify with the gatekeeping role identified the patients as gatekeepers, for several reasons. Patients, they said, could always search until they found a doctor who would do the procedure. Additionally, almost all physicians who would not or could not perform NMSS referred their patients elsewhere and didn’t actively try to stop their seeking it. Finally, physicians protested that they should not be encroaching on patient autonomy, thus making it impossible for them to be gatekeepers.

“I think the patient is her own gatekeeper. It’s a question of whether or not we open it sufficiently for her or provide her other avenues or other entrances through the gate.... So physicians are not necessarily the gate keepers. They might be the ‘gate regulators’.” (1; OB/GYN)

“I think that doctors shouldn’t be gatekeepers. If they perform the procedure and they can do it safely and accurately, the patient should be the driver.” (8; OB/GYN).

Those who identified with the gatekeeping role saw their role as one of responsibility; they needed to be gatekeepers in order to uphold the principle of “do no harm.” One participant acknowledged that she would refuse certain patients because their age made the chances of success so low that she felt it was unethical to allow them to go through the procedure.

“Sometime we have to [gatekeep]—I feel like I’m a protector, almost, of them from themselves.” (4; RE).

At least one OB/GYN felt REs were in the gatekeeping role because they could actually provide the technology. Another participant identified strongly with the gatekeeping role, but acknowledged that her colleagues felt less strongly about discouraging NMSS and were therefore not gatekeepers in the same sense that she was.

NON-MEDICAL TRAIT SELECTION

Non-medical trait selection was discussed in the context of NMSS as the first non-medical use of PGD. Physicians were asked which traits were appropriate for non-medical trait selection, and more importantly, how they drew the line between appropriate and not. They were also asked whether they felt that NMSS was fundamentally different from non-medical trait selection (NMTS). Three physicians spontaneously used the phrase “slippery slope” in reference to their concern that

NMSS would inevitably lead to NMTS. Of the 14 physicians, 12 were decidedly opposed to non-medical trait selection (NMTS) for several reasons. Nature was a major theme in the discussion around NMTS; the importance of evolution was frequently invoked to explain that NMTS would interfere with natural selection.

“So no, I don’t think any nonmedical physical traits, for example, need to be selected for because it’s our heterogeneity that keeps the species strong.” (7; RE)

Another common response was a concern about the potential for unknown traits to be “piggybacking” on selected traits. Given that the majority of genes are still poorly understood, physicians were concerned that selecting one particular trait would affect other traits through gene linkages and perceived this uncertainty as an unacceptable risk.

“I think what the danger is, is that when we are trying to select for and against sort of non-medically indicated traits, we really don’t have any idea what other things could be found on those same genes. What other things we might actually be selecting into our population, which in turn I would think would be very dangerous.” (12; OB/GYN).

The two physicians who were not opposed to NMTS, as well as some who were, agreed that a similar phenomenon had been in existence for 25-30 years already, through donor gamete selection. Because couples could select donors based

on traits like physical features and intelligence, NMTS via PGD was seen as a natural extension of gamete selection.

*"I mean, I think it's no different than a woman picking a sperm donor out of a book."
(8; OB/GYN).*

Additionally, physicians were asked whether they had experience with patients requesting non-medical traits and whether they felt their patients would request them once it became a scientific possibility. Most physicians found the hypothetical idea of NMTS to be, not only realistic, but also problematic. Physicians said that some patients would joke about the idea or ask if it were a possibility but no patients had come in asking seriously about a specific trait.

"I think that [NMTS] will likely come, but I think the moral and ethical and social discourse on this needs to precede the application of the technology. That said, I think we have to stay constantly vigilant about the technologies and how they're applied and I think family balancing, gender selection is a very slippery slope." (13; RE).

"And again, like people are people, and we need to embrace those differences, and not try to eliminate them and the whole eugenics thing and -- yes, not okay." (2; OB/GYN).

Finally, physicians discussed how NMSS was the same as or different from NMTS. Most physicians felt that both NMTS and NMSS were equally unacceptable,,

that they would respond in the same way—by referring the patient elsewhere—and most drew their ethical line at medical necessity, thereby concluding that no traits were appropriate for NMTS. Others saw the two as different. Interestingly, the physicians who felt they were fundamentally different were divided on which type of selection they thought was more problematic.

“I think the difference is in the history of oppression of women.... It carries more weight. I think the male/female thing carries more weight than just eye color or height or intelligence.” (9; OB/GYN).

“Just because I have more money, I shouldn’t be able to pay for a taller, or more intelligent, or more musical, or blue-eyed, or a... whatever child.... The implications are racism and classism and, frankly, forming caste systems.” (9; OB/GYN).

One physician, in talking about her role in non-medical sex or trait selection explained that where she drew the line was problematic because society and technology are constantly evolving.

“You know I’d like to say that I kind of limit it to medical indications although I really understand that that’s a flawed answer because medicine evolves constantly. You know, there might be a time in the future that all of these like specific phenotypic things are considered medical.” (6; OB/GYN).

NMSS AND PARENTING NORMS

Whether they were parents or not, many physicians made statements about parenting values and norms. Often this included the idea that a parent should want a healthy child rather than wanting a particular sex.

“I think both sexes should be fine for your child, for your first child. You know, as long as your child is hopefully healthy... I don’t—I find [NMSS for a first child] personally not acceptable.” (4; RE).

Overall, the majority of physicians were against NMSS for family balancing. For almost all physicians, NMSS for a first child was just as, if not more distasteful, than for family balancing because it implied an inherent value in one gender over the other and was, physicians felt, based on gender stereotypes. Some physicians suggested that, in the case of first children, parents may believe that they have a gender preference, but they don’t know enough about the parenting experience to know that for certain.

“If it’s your first kid you don’t know what to expect so why would you want one sex over the other?... you may want one gender for a first child, but then you actually have the other gender, you’re—you know, may like that more or something.” (5; RE).

Additionally, physicians expressed their impression that parents expect something specific of a “balanced family” that may have more to do with gender stereotypes.

No, I think a lot of people see a value in a family with balance, where, you know, there's a mom and a dad, and there's a daughter and a son. But you know, again though you get into sexual stereotypes. They see the daughter with a Barbie doll and they see the son with a baseball bat or whatever. (13; RE).

Physicians also valued the ideal of parents who accepted their children for who they are. There was a concern that parents were using technology to try to control aspects of their parenting experience that were truly beyond their control and that this would ultimately lead to unrealistic expectations and disappointment.

“I think that an inherent part of parenthood is that you have to understand that you cannot be in control of everything. That is the nature of the human condition, and it is what parenthood maybe teaches better than anything else.” (6; OB/GYN).

“Because it's not about being a happy parent. It's about being a happy parent contingent on a specific outcome, which just {sets up the} dynamic where that child will sometimes disappoint that parent who has an expectation of perfection and it will be taken out on that child. And I just think that coming into parenthood with that mindset that I can create the perfect child is dooming that kid {to never being able to

live up to} whatever the expectation will be, and I just don't think that that kind of psychological trauma is {ever worth} whatever phenotype that the parent is looking for." (6; OB/GYN).

Similarly, participants discussed the importance of valuing people's differences, specifically parents valuing the unique qualities of their children. This norm came up most often in response to non-medical trait selection.

"We need all kinds of people in this world, and designing your child... to be perfect, or whatever you think is perfect, just makes for a very boring society." (11; OB/GYN)

"I mean, why would you want to have everybody have blue eyes, or everybody be brilliant, you know? I think variety is the spice of life." (4; RE).

Valuing the differences among people was also held up as important so that certain traits would not be considered inferior to others.

"I mean [trait selection] devalues the majority of other human beings that aren't of that trait." (4; RE).

Of our participants, 12 of 14 were parents themselves and about half cited their experiences with parenthood as a value that affected their attitudes toward NMSS for family balancing.

"And so, we'll have people who come to do gender selection because they've had girls and they culturally wanted to have a boy. Somehow, being female and having two daughters, you know, I feel uncomfortable with that." (14; RE).

CULTURE AND ETHNICITY

Though we didn't ask about the sex ratio or cultural preferences, a word query in NVivo revealed that "ethnicity" and "culture" came up in all but two of the interviews. Some physicians seemed reluctant or uncomfortable to discuss cultural differences, even though they brought up the topic spontaneously, and most seemed conflicted on the topic; they wanted to respect a couple's cultural values, but didn't want to propagate harmful ideas about gender or contribute to a ratio skew.

"I don't support the concept of male gender preference. I believe that people have a right to do what they want to do culturally but it's not something that I support personally. (3; OB/GYN)

"I find it challenging because in my patient population, which is largely underserved and immigrant populations, the only people that I've had ask for sex selection are people who are asking for male children. And that tends to be a cultural bias against having female children, which as a woman myself, I find somewhat offensive, and I try to separate my personal feelings from my ability to deal with my patients." (12; OB/GYN).

"I don't agree with the cultures that say it's fine to do this. But the reality of it is, more than half the people on the face of the earth live in societies and cultures where this is completely expected. I mean they don't even question it. Over half the people on the planet wouldn't even question it." (13; RE).

DISCUSSION

The purpose of this study was to explore and describe physicians' experiences of and attitudes toward non-medical sex selection via PGD. Hunt and Carnevale's Moral Experience Framework was used in order to underscore the nuances of physicians' experiences, as well as the direction and depth of their feelings, particularly around ethical issues. The study also sought to explore physicians' perceptions of implications, ethical or otherwise, at multiple levels. The third goal was to explore how physicians currently make decisions around NMSS and what role, if any, they preferred to play in the decision-making process recognizing that they may be ideally placed to be gatekeepers of the technology. Finally, this study attempted to elicit the perceived appropriateness of other non-medical traits for PGD, how physicians drew those lines, and whether their attitudes mirrored or diverged from those around NMSS. Analysis of the data revealed nuanced attitudes toward NMSS and non-medical trait selection (NMTS) as well as perceived benefits and harms on multiple levels. Other themes included the specific values that drove physicians' attitudes, as well as a high level of ambivalence around decision-making and gatekeeping. The data from these interviews revealed complex

attitudes and the values behind them, values conflicts and decision-making paradoxes, and ambivalence that prevented the physicians in this study from easily “drawing lines.” These findings underscore the existence and importance of ethical struggles among physicians and have implications for clinical practice as well as professional society regulation.

ATTITUDES AND VALUES

Autonomy and Other Values

According to the American Society of Reproductive Medicine (ASRM), the right to reproductive freedom is not an absolute right, but limitations must have significant justification. This perfectly captures the most common reason for physicians to have a values conflict or ethical dilemma. Patient autonomy is frequently held in higher regard than the other medical ethics principles despite the principles being theoretically equal. Evidently, some of the physicians in our study struggled to reconcile autonomy with other values, especially justice and nonmaleficence, which is significant because no single ethical principle should outweigh another (Puri & Nachtigall, 2010). Most of these conflicts could only be resolved with a “trump,” when the physician chose one value to outweigh the other. Physicians also expressed distress when they found themselves in the position of making a decision in a lose-lose or paradoxical situation; these were the scenarios of site-specific benefit with negative status quo maintenance.

Stern et al (2003) qualitatively studied fertility clinic directors’ reactions to ethically complex cases, one of which was a request for NMSS for family balancing.

Those directors who believed in denying NMSS did so on the basis of their philosophy of medicine; this closely mirrors the value of medical ethics principles that physicians relied on for decision-making in this study. For example, clinic directors were concerned about misuse of the technology or its use for non-disease conditions, both justice-related considerations, also brought up by the physicians in our study. Furthermore, some clinic directors felt NMSS was unethical or a “slippery slope” to other inappropriate uses of technology. Clinic directors who conceded to use NMSS in this hypothetical case cited patient autonomy as the primary determinant even if they believed that the treatment shouldn’t occur. Likewise, though most physicians in our study identified themselves as against NMSS, the vast majority would support a patient who wanted to use it out of respect for patient autonomy.

Clinic directors, in making decisions about NMSS, also discussed discrimination and the potential impact of this technology on the sex ratio and on a woman’s place in society (Stern et al, 2003). Gender equality was a commonly cited value after medical ethics and also complicated NMSS for our physicians. Concern over the sex ratio and the propagation of sexism (in the form of gender roles and stereotypes) were the two greatest harms of NMSS mentioned by physicians in our current study. The current study extended Stern et al’s 2003 study by eliciting non-hypothetical experiences in addition to hypothetical thought experiments. Furthermore, in our study physicians were asked about selection for a first child, the reactions to which may have been based on different values than those identified by the clinic directors. Finally, Stern et al’s study was almost 80% male while this study

is nearly 50% male; if the genders do have fundamental differences in attitudes, then our study was better positioned to capture that.

Puri and Nachtigall's 2010 study compared the attitudes and experiences of primary care physicians (including, but not limited to, OB/GYNS) and physician providers of clinical sex selection services (REs). Once again, medical ethics values emerged as the main predictors of attitudes and behaviors. Whereas in our study, there were seemingly no differences in the values or attitudes of OB/GYNS and REs, Puri and Nachtigall saw distinctly different perceptions of these values in their two physician groups. In part, this may have been because their group of PCPs included OB/GYNs, family medicine physicians, and pediatricians, which may have made the two groups more distinct or polarized in their opinions. Additionally, Puri and Nachtigall reported theoretical saturation within the PCP group, though not the RE group, and the current study may have different findings when more physicians are interviewed. Of the medical ethics principles, autonomy was a primary theme in both studies; in fact, it was the most commonly cited argument both for and against sex selection. Puri and Nachtigall's REs saw NMSS as an expressive of reproductive rights and female empowerment. Their sample of primary care providers (PCPs) felt that patient autonomy was compromised by complex, outside factors, especially social forces, that unduly influenced women's decisions around NMSS.

In our study, autonomy was almost always used in the context of supporting NMSS, but it was the ethical principle and value that seemed most likely to create conflict for physicians. In Puri and Nachtigall, the PCPs questioned whether the legality of abortion "conferred legitimacy on all reproductive choice." Similarly,

physicians in our study who voiced a commitment to women's reproductive autonomy, or pro-choice values, struggled when they felt that respecting a woman's choice was not in her best interest. Interestingly, it seems as though the opposing views that Puri and Nachtigall's groups held were those that were simultaneously held by many physicians in our study, contributing to discrepancies between personal and professional beliefs as well as values conflicts.

Family Balancing and First Children

On family balancing, the ASRM guidelines say that it is not unethical for parents to have a child "of the gender opposite to that of an existing child or children," which is in line with the actions, if not the beliefs, of most of our providers. However, the ASRM says of selecting for a first child that it "would not be unethical for parents to prefer that their first-born or only child be of a particular gender because of the different meaning and companionship experiences that they expect to have." This runs counter to the attitudes of most physicians in our study who believed that selection for a first child was less acceptable, less of a necessity, and based more on gender roles and stereotypes. Puri and Nachtigall's SSTPs did not feel it was within their purview to ask patients the reason for social sex selection.

Unlike Puri and Nachtigall's PCPs, physicians in our study did not discuss the possible effects of NMSS on preexisting children in the family. The two groups did agree, however, that NMSS reflects a "contemporary need to use science and technology to control parts of life previously left to chance" (Puri & Nachtigall,

2010). Our physicians mentioned control in the context of parenting norms and felt it was natural for parents to want to control outcomes, but that people and science are too complex to control. This sometimes led to the concern about parents' expectations of a "designed" child and whether the parents would suffer significant disappointment. Additionally there was concern around whether the child would be appreciated as an end rather than as a means to one, especially if the parents' expectations were not met. Physicians did not speculate about the likelihood of these issues, but some incorporated awareness of expectations into their counseling of patients.

BENEFITS AND HARMS

Culture and the Sex Ratio

Like Puri and Nachtigall's SSTPs, some of our physicians noted that the majority of serious NMSS requests came from certain ethnic groups and, in that case, were almost always requests for males (2010). As a result, REs and OB/GYNs alike were highly likely to mention the unbalanced sex ratio in Asia and list the possibility of sex ratio skew in the US as a potential harm of NMSS. Providers in our sample disagreed as to how likely it was that a skew could occur in the US. They noted that if NMSS was only recommended for family balancing then the result should be an even number of requests for each sex. In a study of fertility clinics across America, of 92 couples undergoing IVF for family balancing between 2004 and 2006, 36 cycles were for females and 56 for males. Overall, this seems to indicate a lack of preference for one sex over the other. However, the patterns in

gender selection were significantly different by ethnicity. Chinese, Arab/Muslim, and Asian-Indian couples primarily selected for males, while other ethnicities (Caucasian and Hispanic) preferentially selected for females. This supports the idea that there are still cultural biases against females in certain populations and that this is an important ethical consideration in the regulation of NMSS. (Gleicher and Barad, 2007).

The ASRM concludes that gender skew and population limitation (through family planning) are too speculative to be important in considering guidelines and recommendations around NMSS. This is in line with the majority of predictions made by participants in our sample, but fails to account for the importance of the issue to physicians. Physicians were wary of the potential for a future skew or of NMSS's indirect implications for the valuing, or devaluing, of both genders. Otherwise said, "ongoing problems with the status of women in the United States make it necessary to take account of concerns for the impact of sex selection on goals of gender equality" (ASRM).

DECISION-MAKING

Preferences for Guidelines and Regulations

Several physicians in our study mentioned a need for current research as a means to create NMSS-related policy; they reasoned that the longer physicians and societies waited, the more likely they were to run into more complex ethical scenarios and find themselves without guidelines. For example, several predicted that the category of "medical" would shift to include traits previously considered

“non-medical.” Likewise, Stern et al conclude that “laws governing new technology tend to lag so far behind the technology itself that they are often in danger of being obsolete by the time the legislation” (2003). Ironically, more than a decade later, this study has reached the same conclusion: physicians are interested in guidelines because of the ethical complexity of a technology with the potential to affect the population or cause significant harm. Though ACOG and ASRM have guidelines, as described earlier, they come to different conclusions and are ultimately unenforceable.

Puri and Nachtigall (2010) found that sex selection providers were averse to regulation of sex selection, seeing it as a threat to patient autonomy and reproductive rights. Given that the nature of their work involved performing elective “patient-driven” procedures, they felt better able to respect patient choice. Likewise, some of our physicians preferred a policy in which they would still retain the power to make decisions alone or, more often, jointly with the patient. Others, however, felt that a blanket ban on NMSS would be their ideal policy. When asked to create their own policy, most participants gave conflicting answers (e.g. saying that a professional society guideline was ideal but not preferred) or were unable to answer. In any event, the ASRM states: “Until a more clearly persuasive ethical argument emerges, or there is stronger empirical evidence that most choices to select the gender of offspring would be harmful, policies to prohibit or condemn as unethical all uses of non-medically indicated preconception gender selection are not justified.” The ASRM statement is largely consistent with the opinions expressed by our participants. Without evidence of a significant problem with empirical evidence,

like a skewed sex ratio, or an ethical argument strong enough to trump the misgivings of providers, many participants did not favor complete prohibition of NMSS. The ASRM, like many of our participants, is unable to draw a hard line on NMSS because of the complexities and nuances of its usage and implications.

The Slippery Slope

The ASRM clearly states that we need to pay attention to ethical and social concerns before assisted reproductive technology is available for non-medical use. To that effect, three physicians brought up the “slippery slope” concern, always in reference to the perceived inevitability of non-medical trait selection (NMTS). The “slippery slope” assumes that there is no clear line between what is appropriate for PGD and what is not. As to this slippery slope concern, the ASRM acknowledges that “[the idea that] offering parental choices of sex selection is taking a major step toward ‘designing’ offspring” is “not unreasonable” (ASRM). Yet, they continue, the slippery slope argument is “overdrawn” since the desire to control the gender of one’s child is “older than the new technologies that make this possible” (ASRM). Essentially, the ASRM seems to agree with our participants that NMSS could lead to NMTS, but that cause for concern should remain low for now. Furthermore, as several participants pointed out, choosing a gamete donor or even a partner (sexual selection, in contrast to natural selection) are also attempts to control the traits of offspring.

IMPLICATIONS FOR PRACTICE AND CONCLUSIONS

Puri & Nachtigall felt that they could have had a sampling bias, having possibly recruited physicians with strong feelings about sex selection. However, having asked as part of the demographics, we know that our physicians were fairly evenly distributed in the strength of their opinion on sex selection. This may be why we didn't find as great a divide between the two specialties and could also play a part in why our physicians tended to report conflicting values and paradoxical beliefs, an amalgamation of the opinions of Puri & Nachtigall's two groups. Puri and Nachtigall called for further research on the effects of sex selection technologies in order to develop evidence-based professional guidelines. This study, like theirs, has uncovered "variety, emotional intensity, and nuanced thoughtfulness of the opinions and concerns" elicited around NMSS and NMTS.

To reiterate an important earlier point, providers in the Puri and Nachtigall study indicated that even if they have only dealt with a small number of sex selection cases in their career, their emotional impact made them memorable in physicians' professional lives. This was part of the rationale for the current study and for the selection of the Moral Experience framework. The experiences described by our physicians bore this out. Major themes revealed across the interviews were those of ambivalence and conflict, and the struggle to "draw a line," whether it was between personal and professional attitudes, between family balancing and selection of the first child, or between medical and non-medical traits, among many others. Physicians communicated that this uncertainty is distressing and often the cause of ethical dilemmas in everyday practice.

In summary, the main findings of this study are as follows. The majority of our physicians were personally, if not professionally, opposed to NMSS and NMTS. The two primary harms of NMSS, as expressed by the physicians, were sex ratio skews and sexism. Autonomy played the most important part in determining a physician's behavior around NMSS. Belief in patient autonomy was also the value most in conflict with other values, though it could be occasionally trumped by justice or "do no harm." Some physicians were concerned that parents exert too much control over their reproduction and this may result in disappointment of expectations as well as a failure to value the differences among people. Some physicians would prefer a blanket ban on NMSS, while others feel that professional societies should be responsible for creating guidelines or regulations that are not so restrictive that the provider cannot go against them if their better judgment demands.

There have been many calls for additional research into the ethics of NMSS so as to create useful professional guidelines that are not too restrictive of providers or their patients, but also provide guidance as technology evolves and ethical dilemmas arise. This study provides evidence for the nuanced attitudes that physicians have toward NMSS as well as the values that shape these attitudes. What has emerged is the importance of patient autonomy, but also the need for permission to allow justice or "do no harm" to weigh as heavily in internal debates as autonomy. Since physicians prefer to make joint decisions with their patients, we can imagine that allowing them the time to counsel their patients about expectations and discuss society-level implications will become increasingly important as the technology

becomes easier to access. Lastly, our data suggest that it is important that regulations be flexible enough to allow technology to evolve, but also that they set boundaries to diminish the chances of ethical dilemmas.

DEMOGRAPHICS

No definitive statements can be made about the effects of demographic variables on responses and patterns because of the low number of respondents and lack of thematic saturation. That being said, certain questions were added to the demographics questionnaire based on previous studies with evidence suggestive of differences among certain groups. Parenting status was of interest because respondents (OBGYNs) in the Caldas et al study (2010) were more likely to approve of PGD if they had children themselves. In our study, 12 of 14 physicians were parents so they could not be compared to the group of 2 non-parents. However, as being a parent was a value cited by many of these physicians, it is not unlikely that greater numbers of participants could reveal a difference in trends between parents and non-parents.

Sex was of interest because male physicians were significantly more likely to approve of PGD than female physicians in the Caldas et al study (2010). Males and females in this study did not apparently differ on how likely they were to approve of NMSS nor did they appear to differ in their attitudes or level of conflict. Additionally, specialty and type of workplace are important given that respondents practicing in ART settings were more agreeable to PGD (Caldas et al, 2010).

It is worth noting that there do not appear to be differences in the attitudes of OB/GYNs and Res thus far. Their experiences differ as a function of their different specialties, but REs list approximately the same number of benefits and harms as OB/GYNs. It may be that REs who work in clinics that offer NMSS are more neutral around family balancing than other REs or OB/GYNs, but there is not yet enough data to explore whether the specialties feel similar levels of conflict. There seemed to be an equal number of physicians responding to hypothetical scenarios and referring to lived experiences. This didn't seem to vary systematically with any attributes, nor did it seem to affect attitudes. Lastly, strength of opinion about NMSS only seemed relevant to number of harms and benefits listed, with "not strong" participants listing fewer of each, though they didn't differ in content.

LIMITATIONS AND FUTURE DIRECTIONS

The most important limitation of this study is the low number of participants and therefore our inability to reach thematic saturation. The number of participants also made it uninformative to compare sub-groups on demographic characteristics or other attributes. The study was not intended to be generalizable to all OB/GYNs and REs; future quantitative studies, based on the initial qualitative work, would be able to recruit enough physicians to have generalizable results. Future quantitative work could focus on a variety of relevant topics including mediators of decision-making; moderators of conflict between personal and professional attitudes; the demographic factors that predict a physician's values, attitudes, or behaviors; a forced-choice design to better understand which values commonly outweigh other

values; and others. Another potential problem is the use of one interviewer for all interviews. Although the interview guide was designed with the input of several people, and worded to be as neutral as possible, it's possible that any biases of the interviewer had some effect on the direction of the interview.

Though we chose the two specialties of medicine carefully, we did exclude other stakeholders and potential gatekeepers. Future studies could try to ascertain why it is that certain providers identify as gatekeepers and others don't.

Furthermore, if genetic counselors have the potential to be gatekeepers or at least be involved in PGD, it would be important to assess their values and current practices. Through her conversations with genetic counselors about various uses of PGD, Everton (2014) found that 71% agreed that PGD should not be used for sex selection. Because of the absence of genetic counselors in reproductive endocrinology, 25% of Everton's sample were concerned that REs would use PGD inappropriately.

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APPENDICES

APPENDIX A : RECRUITMENT LETTER

Dear Dr.

I am a graduate student working with investigators from the Johns Hopkins University Bloomberg School of Public Health and National Human Genome Research Institute as part of my Master's thesis for the Genetic Counseling Training Program. We are interested in physicians' attitudes toward and experiences of non-medical sex selection (NMSS). The purpose of this research is to learn more about physician's experiences with and attitudes toward prenatal genetic diagnosis (PGD) for non-medical sex selection. You are eligible to complete this survey if you are currently providing care to patients.

The study will involve conducting one-time telephone interviews with a sample of physicians (OBGYNs and reproductive endocrinologists). Although the length of time will vary depending on participants' responses, we expect that each interview will take about 30 minutes. If you are not interested in participating in a telephone interview, or in learning more about the study, please respond to this letter using the attached postage-paid envelope. If we don't receive your request for no further contact, we will contact you by telephone in one week to ask about your interest in joining this study.

The conceptual framework of this study is modeled on Hunt and Carnevale's Moral Experience framework. The moral experience framework encompasses a person's sense that the values important to them are being realized or thwarted in everyday life. As such, this is an opportunity to reflect on ethical issues surrounding the use of PGD for NMSS. We are interested in learning whether there are conflicts that you feel around this topic. We are interested in your personal opinion, which we realize may or may not reflect the policy of the institution with which you are affiliated.

The potential risks from completion of this survey may be psychological distress from being reminded of difficult patient care experiences. You will be free to stop the interview at any time. If you decide to complete the interview, we will take several steps to protect your confidentiality. Data from this study will be identified with a code number and not your name. The code number allows us to keep track of who has not responded so we can send follow-up materials. The link between participant names and code numbers will be safeguarded and destroyed when the interviews are completed. Your name will never be used when reporting any of the results. Only summary aggregate data will be reported.

Thank you for your consideration.

Sincerely,

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APPENDIX B: CONSENT FORM

Protocol Title: Physicians' Experiences with and Attitudes toward Non-Medical Sex Selection through Preimplantation Genetic Diagnosis

Protocol No.: T-HG-0107

Sponsor: National Human Genome Research Institute (NHGRI)

Principal Investigator: Barbara B. Biesecker, MS, CGC
Associate Investigator, Social & Behavioral Research
Branch, NHGRI Bethesda, MD

Dear Physicians,

You are invited to participate in a study conducted by researchers at the National Institutes of Health and the Johns Hopkins University.

Why is this study being done?

To learn more about how physicians experience, understand, and possibly struggle with non-medical sex selection. We are interested in hearing from physicians about the individual- and society-level ethical implications of NMSS, if any, as well as their role in NMSS decision-making, and their opinions as to the appropriateness of other hypothetical non-medical traits.

We plan to enroll OBGYNs and reproductive endocrinologists who currently see patients.

Who can take part in this study?

You must be 18 years of age or older and must be an English-speaking OBGYN or reproductive endocrinologist currently practicing in the US.

What is involved in this study?

There is one interview that takes approximately 30 minutes to complete. It will be conducted with one of the investigators (NH) over the phone and recorded to be transcribed later.

What are the risks of the study?

There are no known risks of taking part in this study. If taking the interview makes you feel uncomfortable, you can stop taking the survey at any time. If it causes you discomfort, you can contact the researchers (below) and they will help direct you to appropriate resources.

Are there benefits to taking part in the study?

You will not personally benefit from taking part in this study.

Do I have to participate?

No, you do not have to take part in this study if you do not want to. If you begin the interview, you can choose to skip any question that you don't want to answer. You can also stop the interview at any time.

Will I be compensated for my participation?

You will not receive financial compensation, but the researchers are offering to share the results of the study with you if you would like.

How will your privacy be protected?

We will take several steps to minimize the likelihood of a breach of confidentiality. Your name will not be linked to the transcribed interview; only your demographic information will be linked to your responses. Only summary aggregate data will be reported.

Your signature is not required. You will be sent this consent form prior to your interview. On the day of your interview, the interviewer (NH) will read the consent aloud. If you agree to participate, you will give verbal consent that you understand the consent form.

Thank you for your interest and time! Please print a copy of this consent form so that you have the researchers' contact information.

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APPENDIX C: INTERVIEW GUIDE

The interview will not necessarily follow this guide directly. Sections may be discussed in different orders, depending on the direction in which the interviewee takes the conversation. However, every effort will be made to cover each section at some point during the interview.

I.

- Have you had a patient ask about or request non-medical sex selection, either for family balancing or a first child? What did you think about this request? How did you feel about this request? How did you respond?
 - (For all physicians, read the following vignettes and prompt the same follow-up questions for each: A couple comes into your office asking about/for family balancing services because they have two children of the same sex and would like to ensure that their next child is the other sex. Now consider that the couple is requesting non-medical sex selection to determine the sex of their first child. Imagine the “usual” type of couple that can afford to access NMSS via PGD (e.g. Caucasian, higher socioeconomic status) rather than your (the physician’s) usual type of patient because some of you work with populations who rarely or never have access to PGD for economic or cultural reasons.
- Have you ever brought up NMSS with a patient? Why or why not? Can you imagine a context in which you would want to bring it up? What would that be?

II.

- What do you see as possible implications, both positive and negative, of NMSS? What do you see as possible benefits and/or harms to a couple? To the provider? To the practice? To society?
- Do you talk to your patients about any of these implications of NMSS? If so, which ones and how? If not, why not? Can you imagine talking about this with patients?
- When people have to think through difficult issues, they often consider what values or beliefs are important to them. What things that you value, things that are important to you, and beliefs that you hold, influence how you think and feel about NMSS? (Prompt: These may include professional beliefs (what it means to be a doctor), religious beliefs, moral beliefs, political views, or other values that are important to you.) Can you talk through an example of how each value has affected your thinking or practices about NMSS?

III.

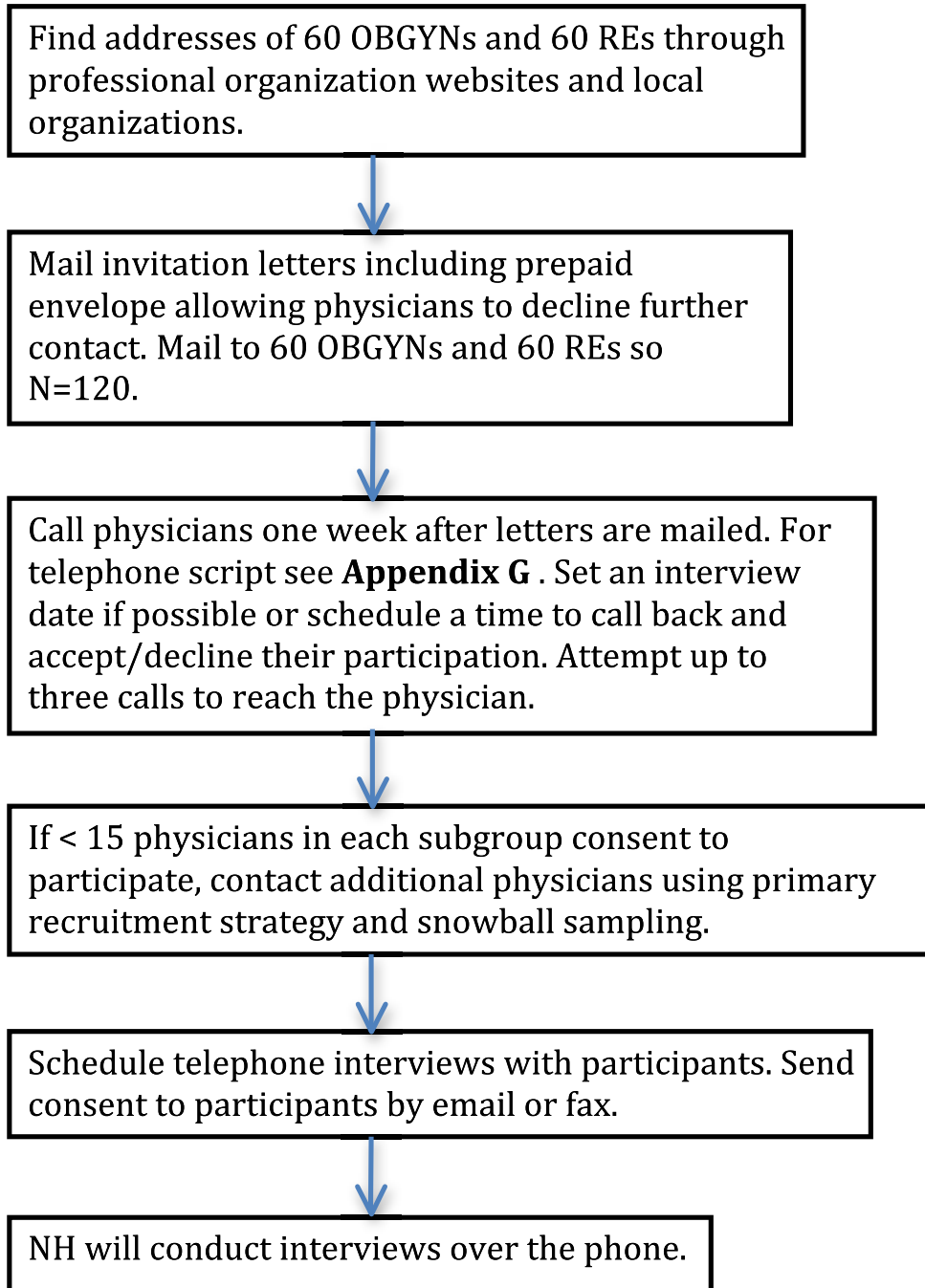
- Where you work, who makes decisions about recommending and/or offering NMSS to patients? How do you feel that is working in your practice?
- Do you see yourself/physicians generally in a gate-keeping role for NMSS? In what ways?
- Who do you think should have the power to make decisions about NMSS? (Prompt: The individual physician? The couple? The medical center? A professional society? A combination?) Why?

- If you could create policy around NMSS, what would it be and why? (First for your institution then, more broadly, do you think there should be a national policy? What would that look like? How specific would you want the guidance from a national body to be? What should it include?)

IV.

- What non-medical traits are appropriate or inappropriate for PGD? Why are or aren't they appropriate? Is NMSS different from selection of other non-medical traits? (Examples if needed include physical traits, cognitive abilities, talents/skills, etc.)
- How do you decide where you (personally, professionally) draw the line between appropriate and inappropriate traits?
- Have patients asked about the possibility of selecting for or against other non-medical traits? (Prompt physicians' feelings and emotional experience beyond the yes/no answer.)
- What non-medical traits do you foresee your patients requesting? How would you respond to these requests?
- Are there any other thoughts that you want to share on this topic broadly that I haven't thought to ask about?

APPENDIX D: PROCEDURE OVERVIEW



APPENDIX E: DEMOGRAPHICS QUESTIONNAIRE

Now we'd like to ask you a brief series of demographic questions. This information helps us to ensure that we recruit a diverse sample of physicians. Only summary aggregate data will be reported.

Are you currently seeing patients?

What is your age?

What is your gender?

- ☐ Male
- ☐ Female
- ☐ Other

What is your medical specialty?

- ☐ OB/GYN
- ☐ Reproductive Endocrinology

In what part of the country do you work?

- ☐ Northeast (CT, ME, MA, NH, RI, VT, NJ, NY, PA)
- ☐ Midwest (IL, IN, MI, OH, WI, IA, KS, MN, MO, NE, ND, SD)
- ☐ South (DE, FL, GA, MD, NC, SC, VA, Washington D.C., WV, AR, LA, OK, TX)
- ☐ West (AZ, CO, ID, MT, NV, NM, UT, WY, AK, CA, HI, OR, WA)

For how many years have you been in practice?

What kind of workplace do you work in? (For example: clinic, hospital, private practice.)

- ☐ Clinic
- ☐ Hospital
- ☐ Private Practice
- ☐ Other

The following questions will help us characterize your typical patient population:
Roughly what percentage of your patients are Caucasian? Hispanic? African-American? Asian?

Roughly what percentage of your patients are on public assistance?

Roughly what percentage of your patients have a household income over 200,000 annually?

Roughly what percentage of your patients are under 25? Between 25 and 35? Over 35?

Are you yourself a parent?

- ☐ Yes
- ☐ No

How strong are your feelings toward non-medical sex selection? Please choose one: not strong, somewhat strong, strong, or very strong.

Have you been involved in debates or policy considerations regarding non-medical sex selection?

☐ Yes

☐ No

APPENDIX F: OPT-OUT LETTER

I, *(please print your name)* _____, decline to participate in the study Physicians' Experiences with and Attitudes toward Non-Medical Sex Selection through Preimplantation Genetic Diagnosis. By sending this letter back to the researchers, I am declining further contact with them and understand that I will not receive any additional follow-up phone calls about this study.

(Please sign your name) _____

APPENDIX G: CODEBOOK

As of January 2015

100 Against NMSS

101 Reasons against

200 Benefits of NMSS

201 Individual

202 Couple/Family

203 Provider

204 Societal

205 None

300 Conflicting Values related to NMSS

Use anytime the participant talks about how their personal values might be in conflict.

301 Trump

When a values conflict is resolved because the physician allows one value to “trump” another. For example, a physician resolves their conflict around discouraging NMSS by allowing their value of nonmaleficence (“do no harm”) to trump their value of patient autonomy.

302 Ethical Dilemma

This is used when a physician explicitly identifies something as a “moral” or “ethical” dilemma.

400 Decision-Making

Who makes decisions/should make decisions about NMSS, which may be double coded with a time orientation such as currently it is up to the physician (402 and 406) but I prefer it were up to ACOG (404 and 408).

401 Patient only

402 Physician(s) only

403 Joint (Patient and Physician)

404 Professional Society or Government/Legislature

405 Uncertain- use for uncertainty or ambivalence about who should make decisions or what policies should be.

406 Current – use for discussions about current practices

407 Future – use for discussions about what should/will happen in the future

408 Preferred- use for discussions about who the participant thinks should make decisions or how they should be made

409 Gate-Keeping- use whenever participant talks about his/her role or the profession’s role as gatekeeper; this includes discussions about why someone is *not* a gatekeeper.

500 Ethnicity and Culture

Use for any discussion about ethnicity or culture.

600 Expectations

This does not refer to the participant's expectations but rather when the participant talks about the expectations of their patients such as expectations of a child based on gender roles or the expectation of perfection.

700 For NMSS

701 Reasons for

800 Gender – use to code for any discussion about gender

801 Gender Roles

802 Sexism

900 Harms of NMSS

901 Individual

902 Couple/Family

903 Provider

904 Societal

904.1 Sex Ratio- Use any time someone mentions the possibility of a sex ratio skew or refers to the sex ratio in other countries, even if they deem it unlikely.

905 None

1000 Hypothetical

If the physician is discussing hypothetical cases, rather than lived experiences.

Double code with other codes as appropriate.

1001 Family Balancing – use for discussions based on the hypothetical case related to a second/third/etc child

1002 First Child – use for discussions based on the hypothetical case related to a first child

1100 Non-Hypothetical

If the physician is referring to his/her experience with actual cases, though not necessarily to one case in particular. Double code with other codes as appropriate

1101 Family Balancing – use for discussions of actual cases with requests for family balancing.

1102 First Child – use for discussions of actual cases with requests for NMSS for a first child.

1200 Nature

Any reference to nature or what is natural including evolution and mate selection.

This can include references to God if appropriate e.g. It's unnatural to play God.

1201 Random or Chance

1202 Non-Random or Predetermined

1203 Predetermined Randomness

When there are conflicting ideas in a single thought. For example, saying that a goal of evolution is randomness or that gender needs to be random to end up with the child one is supposed to have. Basically, when you would double-code for the previous two codes in one thought.

1300 Other Non-Medical Traits

1301 Against NMT Selection (with or without reasons)

1302 For NMT Selection (with or without reasons)

1303 Comparison to Sperm or Egg Donation

1304 Predictions about what will happen with this in the future

1304.1 "Slippery Slope"

1304.2 "Eugenics"

1304.3 Specific Traits i.e. Blue Eyes

1305 Compared to NMSS

1400 Personal

Whenever the physician is referring to their personal feelings, ideas, thoughts, etc. Often this is in contrast to Professional. Usually the quote includes "Personally" or "My Personal." Should be double-coded with other codes.

1500 Professional

Whenever the physician is referring to their professional actions or the policies of their workplace. This is often used in contrast to Personal. Should be double-coded with other codes.

1600 Larger Issue

This code may be used when a participant is talking about being for, being against, or being conflicted about NMSS. This applies when the participant talks about how NMSS is being used/could be used/shouldn't be used as a solution to a larger societal problem (eg, selecting for a boy because girls are poorly treated). The physician may acknowledge that choosing a gender is the result of a greater societal problem and will not help change or rectify that problem, except possibly on an individual level, and may even exacerbate that problem on a societal-level.

1700 Values

One's judgment of what is important in life.

1701 Medical Ethics Principles (Beneficence, Do No Harm, Justice, Autonomy).

1701.1 Justice. This may include themes around Frivolous or Unnecessary, Access, Allocation of Resources, or Financial Burden.

1701.2 Non-Maleficence (Do No Harm). This may include Bodily Harm or Physical Danger of the medical technology itself or from another person e.g. a husband.

1701.3 Autonomy. This may include Respecting the Patient's Decision, Being Pro-Choice.

1701.4 Beneficence. This may include Wanting to Help Patients or the Patient's Best Interest.

1702 Parenting Norms.

This is appropriate when a physician talks about how parents should or should not

feel about or act toward their children. This can also be used when the physician

talks about how parenthood or child-bearing are typically done (aka the current

norm).

1703 Valuing Differences.

Variety is the spice of life. This can come up for NMSS or NMTS.

1704 Being a Parent.

This is used when the participant talks about the influence on their beliefs and ideas of being a parent themselves.

1705 Gender Equality.

This is used when the participant talks about Being a Feminist, or Valuing Gender Equality, or being distressed by the valuing of one sex over another.

1706 Other Values.

This might include religious, cultural, political, scientific (e.g. evolution; discarding embryos) or other values. Also a catchall when it's a professional value that doesn't fit into medical ethics.

1800 Significant Quote – use whenever something is an especially enlightening quote. Will likely be double-coded with other codes

APPENDIX H: INTERVIEW SUMMARY SHEET

Date of interview: _____

Interview start time: _____

Interview end time: _____

Brief description of NMSS anecdote:

Interview question(s) most responsive to:

Interview question(s) least responsive to:

Overall impressions of interview:

Categories or major themes in interview:

New or different information (from previous interviews):

Suggestions for subsequent interviewees:

APPENDIX I: ALTERNATIVE TELEPHONE SCRIPTS

For early eligible respondents and respondents with underrepresented characteristics:

Hello Dr. _____,

Thank you for your interest in our study! We would like to welcome you to the study and invite you to schedule your interview. We will look at our schedules to find a date and time that will work for you. We will send you the consent form for this study in advance of your telephone interview; would you prefer to have this mailed or faxed to you? Thank you again for your interest and your time.

For later or respondents with overrepresented characteristics:

Hello Dr. _____,

Thank you for your interest in our study! Because of the number of respondents, we are asking if we can call you back by (date) to let you know if you qualify for this study. We look forward to being in touch with you again soon. Thank you again for your interest and your time.

CURRICULUM VITAE

NINA V. G. HARKAVY

EDUCATION

Johns Hopkins University, Baltimore, MD 2012-2015

National Human Genome Research Institute, Bethesda, MD

Genetic Counseling Training Program

Master of Science- Genetic Counseling

Vassar College, Poughkeepsie, NY

2008-2012

B.A. in Psychology, Correlate in Ecology/Evolution

CLINICAL TRAINING

Prenatal

The Harvey Institute for Human Genetics at Greater Baltimore Medical Center
Towson, MD

Medstar Franklin Square Medical Center Baltimore, MD

Cancer

The Harvey Institute for Human Genetics at Greater Baltimore Medical Center
Towson, MD

Pediatric

Johns Hopkins University, Institute of Genetic Medicine Baltimore, MD
Kennedy Krieger Institute, Neurology & Developmental Medicine Baltimore, MD

Research

ClinSeq Study, National Human Genome Research institute, NIH Bethesda, MD

Specialty

Johns Hopkins Arrhythmogenic Right Ventricular Cardiomyopathy Program
& Johns Hopkins Center for Inherited Heart Disease Baltimore, MD

Johns Hopkins "DNA Diagnostics" Laboratory Baltimore, MD

Columbia University- Division of Movement Disorders Manhattan, NY

Publications and Presentations

Harkavy, N., Erby, L., & Smith, K. (2014, December). *Physicians' Experiences with and Attitudes toward Non-Medical Sex Selection through Preimplantation Genetic Diagnosis: Preliminary Results*. Poster session presented at the National Human Genome Research Institute Scientific Symposium, Bethesda, MD.

Harkavy, N. (2014, November). *Psychological Impact of ICD Placement in Young Cardiac Patients*. Presentation delivered at National Human Genome Research Institute Post-Clinic Conference, Bethesda, MD.

Harkavy, N., Erby, L. (2014, September). *Facilitating Genetic Counselors' use of Qualitative Research*. Presentation for the Research Special Interest Group (SIG) at the NSGC 33rd Annual Conference, New Orleans, LA.

Harkavy, N., Erby, L., Smith, K., Lawson, C., Geller, G., Krasnewich, D., Biesecker, B. (2013, December). *Physicians' Experiences with and Beliefs about Non-Medical Sex Selection through Preimplantation Genetic Diagnosis*. Poster session presented at the National Human Genome Research Institute Scientific Symposium, Bethesda, MD.

Harkavy, N., Hooker, G., & Biesecker, B. (2013, October). *Intersex differences: Implications for genetic counseling practice guidelines*. Abstract for poster at the National Society of Genetic Counselors (NSGC) 32nd Annual Conference, Anaheim, CA.

Harkavy, N. (2013, April). *Deconstructing Denial: Denial as a Coping Mechanism and the Mimics of Denial*. Presentation delivered at National Human Genome Research Institute Post-Clinic Conference, Bethesda, MD.

Counseling, Mentoring, and Teaching Experience

Johns Hopkins' CASE (Community Adolescent Sex Education) Program Teacher
Baltimore, MD
Fall 2012

Vassar College's "The Listening Center" Crisis Hotline Listener
Vassar College, Poughkeepsie, NY
Fall 2009- Spring 2012

Exploring College (Vassar College's Urban Education Initiative) *Mentor, Tutor, and Summer Camp Counselor*
Vassar College, Poughkeepsie, NY
Fall 2009- Spring 2012

Planned Parenthood *Community Outreach/Education Volunteer*
White Plains, NY
Summer 2009

Honors & Awards

Pre-Doctoral Fellowship, National Human Genome Research Institute
2012-2015

General Honors, Vassar College
2012

Departmental Honors in Psychology, Vassar College
2012

Memberships

National Society of Genetic Counselors , Student Member	2012-2014
Psi Chi International Honor Society in Psychology	2012